

# To dialyse or Not


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Ethical decision making in caring for patients with ESRD shares many common elements of ethical decision making with other areas of medicine. There are features unique to the patients with ESRD, however.

## Common principles of ethical decision making for all medical care include the following:

- **Beneficence:** defined as doing what is best for the patient,
- **Nonmaleficence:** defined as doing no harm to the patient,
- **patient autonomy:** defined as allowing the patient to determine for himself what is best.
- **Justice:** defined as evolving what is a proper balance between the patient and the environment in which he lives.

## Features of care for the patient with chronic renal disease which are unique include following:

- the chronicity of survival by artificial means
- the complexity of the patients' diseases,
- the fact that the burdens of treatment may often outweigh the perceived benefits of treatment,
- the long-term physical, emotional, and financial cost to the patient, his family, and society.



# The Demented Patient Who Declines to Be Dialyzed and the Unhappy Armed Police Officer Son: What Should Be Done?

## Case Presentation

A 75-year-old woman with advanced dementia who resides in a nursing home has been on hemodialysis for 12 months. She lacks decision-making capacity and her son, who is a police officer, is the patient's medical power of attorney representative. She was transferred to the present dialysis center from another center, where the decision to start dialysis had been made with a different nephrologist. This nephrologist had discouraged the son from initiation of dialysis for the patient because of her poor prognosis. At the present dialysis center, despite multiple face-to-face sessions during which time the son was further educated about his mother's poor prognosis, he insisted on continued dialysis to prolong his mother's life as long as possible, regardless of her level of function. The hospital lawyers inform the Medical Director of the dialysis center that he is required by state law to continue dialyzing this patient if her legally-designated decision maker insists on it. The patient routinely starts to refuse dialysis whenever she is brought to the dialysis facility from the nursing home. Her son insists that the dialysis center is legally required to dialyze his mother against her will, even if that entails physically restraining her. The dialysis center declines to do so, and the ESRD Network supports its decision. The son instructs the dialysis nurses to call him whenever his mother refuses to dialyze so

*Clin J Am Soc Nephrol* 9: 804–808, 2014.

that he can come in person and try to change her mind. When the son is not available, the patient is returned to the nursing home without receiving dialysis. The son threatens to sue the dialysis center if it does not dialyze his mother each time she arrives for a treatment. The nurses learn that they can coax the patient to stay on dialysis by offering her candy, and, temporarily, the impasse with the son seems to be averted.

Subsequently, the patient's dementia deteriorates, and on two separate occasions, she tries to pull out her dialysis needles. The Medical Director and dialysis staff educate the son about the risk of exsanguination and require him to provide a sitter for his mother during dialysis to ensure her safety. The son reluctantly agrees to sit with his mother during dialysis. He shows up three times a week wearing his police uniform and gun. He tries to stipulate which dialysis staff can care for his mother, intimidates the staff by continually peering over their shoulder, loudly criticizes the competence of some nurses to their faces, and creates a very hostile environment. In another face-to-face meeting, the son is informed that it is against unit policy to bring weapons into the dialysis center and that he should refrain from doing so. He responds that, according to state law, he is entitled to wear his uniform and gun anywhere, even when he is off duty. In fact, he claims that the dialysis unit should be grateful for the extra protection that he is providing.



**Table 1. Unique features of outpatient dialysis centers relative to other outpatient medical settings**

- 1 Frequency of contact (three times per week versus typically a few times per year)
- 2 Duration of each contact (3–4 h versus 10–60 min)
- 3 Presence of other patients (multiple other patients present versus one-on-one visit)
- 4 Therapeutic community of patients and caregivers rather than an individual provider–patient interaction
- 5 Close proximity of patients, which increases the likelihood that one patient's behavior might disturb others and that patients might be exposed to other patients' blood and body fluids
- 6 Risk of patient exsanguination within minutes from needles dislodged from an arterial circuit and risk of blood-borne pathogen exposure to other patients from exsanguination

# Should an Elderly Patient with Stage V CKD and Dementia Be Started on Dialysis?

Irene Ying,\* Zoe Levitt,<sup>†</sup> and Sarbjit Vanita Jassal<sup>†</sup>

*Clin J Am Soc Nephrol* 9: 971–977, 2014.

## TECHNOLOGICAL IMPERATIVE

### Physician

- "I can, I should"
- Financial gain
- Fear of failing the patient
- Fear of failing colleagues
- Fear of litigation
- Overestimating benefit of therapy

### Society & Patient

- Passive acceptance of suggested therapy
- Fear of death
- Fear of failing family or patient
- Fear, as substitute decision-maker, of doing wrong (Guilt)
- Underestimate risk of harms from therapy

## PREMATURE FATALISM

### Physician

- "It won't work, don't try"
- Responsible use of medical resources
- Overestimation of harm of therapy
- Underestimating a patient's quality of life on therapy
- Incomplete services and resources

### Society & Patient

- Passive acceptance of suggested therapy
- Distrust in or aversion to medical system
- Unrealistic optimism regarding patient's health situation

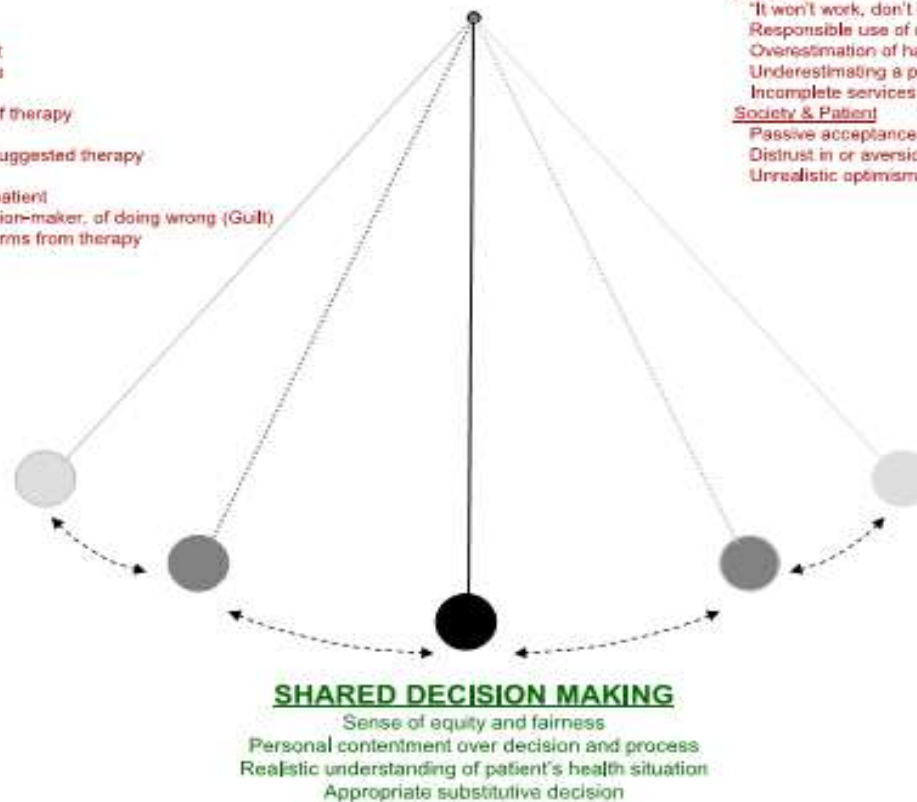


Figure 1. | Potential for a pendulum-like swing from an overreliance on technology to the other extreme of underuse of technology due to a prematurely fatalistic outlook.


# Case Report

- Male, 85y old with CHF, CKD(2ry to HTN) and severe dementia.
- C/O: Dyspnea not responding to diuretics
- Nephrology consult.: dialysis is required but ???HD or ??PD
- The physical & mental state of the patient-----→PD
- He was improved by PD
- He had difficulty accepting the procedure of PD-----→draw or twist a PD tube.
- Hence, we supposed that even PD would be quite burdensome for his family as a caregiver.
- Readmitted suffering from a swollen scrotum, diagnosed as a communicating hydrocele from a hypogastric hernia complicating PD.



# Cont.,

- The family did not want further treatment due to further pain and physical burden for the patient and the risks associated with the operation.
- Judging by his urinary volume, his residual renal function would be maintained for several weeks.
- He had a right to live a peaceful and painless moment for the last period. Withdrawal from dialysis (WD) and palliative care as an optional treatment were proposed (147 days).

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- During this terminal phase, he was readmitted to hospital, and after the family's agreement on the risks of opioid therapy, he was administered morphine to reduce dyspnea.
  - Palliativists played a major role in this treatment which lasted 7 days. He passed away peacefully, with dignity surrounded by his family.

## Case Report

# Withdrawal from Dialysis and Palliative Care for Severely Ill Dialysis Patients in terms of Patient-Centered Medicine

Hideaki Ishikawa,<sup>1</sup> Nao Ogihara,<sup>1</sup> Saori Tsukushi,<sup>1</sup> and Junichi Sakamoto<sup>2</sup>

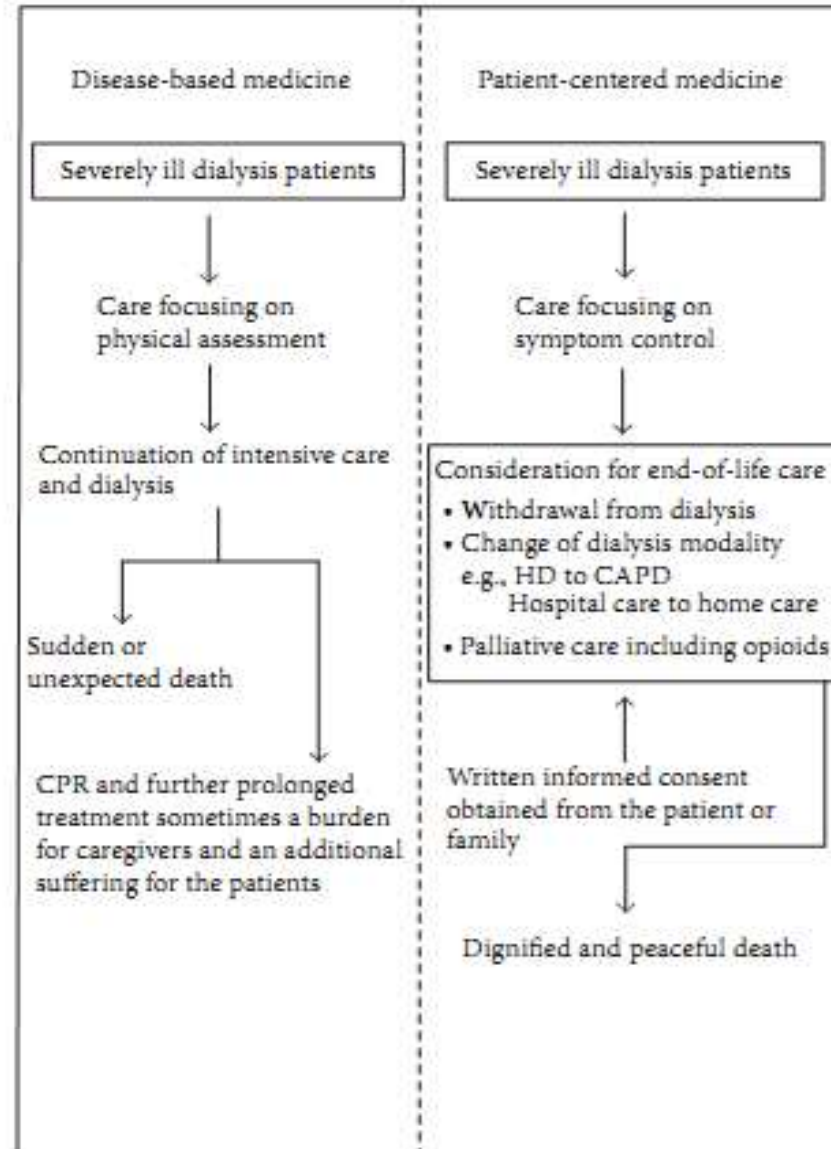



FIGURE 1: Concept of seriously ill dialysis patients showing a comparison between disease-based and patient-centered medicine. To ensure a peaceful death for these patients it is necessary to have cooperation between medical staff members such as dialysis nurses, social workers, and home doctors and nurses. Sufficient time is required to arrange the care for each patient. We consider that these clinical practices are consistent with patient-centered medicine.

# WHAT DO YOU THINK?

1. A case of malign. Ureteric obst. (invasive UB cx.)
  - C/O: high SCr, Hyper K, metab. Acidosis
  - US: Atrophic both kid.
  
2. ESKD in LCF pt. with:
  - Chronic HE
  - Severe hyperbilirub. and hypotension



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- National Kidney Foundation (NKF) set about to establish guidelines for us to use in having discussions with patients.
  - They are not intended to be rules and regulations, but are intended to be utilized as tools in discussing dialysis initiation and withdrawal with patients.
  - The guidelines are based upon the recommendations of the Panel on Initiation and Withdrawal at the NKF Controversies in Quality of Dialysis Care Consensus Conference in 1994

# Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

JOHN H. GALLA

*Renal Physicians Association/American Society of Nephrology Working Group, Washington, DC*

# Moving Points in Nephrology

Withholding and Withdrawing Dialysis in the Intensive Care Unit: Benefits Derived from Consulting the Renal Physicians Association/American Society of Nephrology Clinical Practice Guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Samir S. Patel\* and Jean L. Holley†

*Clin J Am Soc Nephrol* 3: 587-593, 2008.

# Recommendations Summary

1. Decisions on whether to initiate or withdraw dialysis therapy are patient specific and culturally, religiously and ethically sensitive decisions. These decisions can only be made on an informed basis by the individual patient/surrogate after consultation with the care team and others.





## Cont.,

2. It is unethical to use mandatory standards including a patient's age, life expectancy, quality of life, intellectual or physical limitations, socio-economic status or psychological condition in determining whether to initiate or withdraw dialysis.

# Cont.,

3. The patient's values, preferences and goals are major factors, but not absolutely controlling, in the decision making process regarding initiation or continuation of dialysis.
- While the patient/surrogate has the right to request the initiation or continuation of dialysis treatment, the physician has the right to request the right to refuse to provide treatment which in his/her best professional judgment is the medically useless; for example, where the patient is in a persistent vegetative state or is suffering from severe, irreversible dementia.

# Cont.,

4. A patient who has the capacity to make his/her own medical decisions has an absolute right to make a decision not to initiate or to withdraw dialysis therapy. His/her decision in these circumstances should be controlling.

# Cont.,

5. If quality of life or level of mental functioning is used to justify a decision not to initiate dialysis or to withdraw dialysis and the patient has the capacity to make medical decisions, it is only the patient's perception of his or her quality of life or level of functioning that should be utilized.





## Cont.,

6. Use of medical treatment, including dialysis, is not legally or ethically required where the patient will receive no substantive benefits from such therapy.

# Cont.,

7. In circumstances where a patient with ESRD is being evaluated for initiation of dialysis, it is recommended that dialysis be withheld where the patient:
- a: is adequately diagnosed to be in a persistent vegetative state.
  - b: has an irreversible and severe mental disorder that results in the patient being unable to react to or interact with his/her environment (e.g. advanced Alzheimer's disease or severe stroke).
  - c: is expected to die within 60 days from a primary, non-renal disease, unless the patient has an overriding short term life goal that could be met by initiation of dialysis therapy.

## Cont.,

8. In cases where the benefits and burdens of initiation of dialysis for the patient are unclear, it is appropriate to recommend a trial period of dialysis of approximately 30 days.
9. Areassessment of all patients initiated on dialysis is appropriate after approximately 90 days of dialysis.

## Cont.,

10. In cases where the patient/surrogate is considering or desires to withdraw dialysis and the health care team believes that there are possible interventive measures which could reverse the patient/surrogate's desire to withdraw, it is appropriate to recommend a trial period of 30 days, or such time as is necessary for an assessment of the effectiveness of the interventive measures.



# Cont.,

11. There are no Federal or state laws or judicial decisions which permit the health care team and/dialysis facilities to unilaterally withdraw dialysis therapy from a patient who is abusive, persistently disruptive or “non-adherent” with his/her dialysis regimen.

# Cont.,

- We, as individuals and as a society, are in an evolutionary process, so it is appropriate to view ourselves as unfinished parts of a greater whole that will continue to evolve to a more finished product.
- The development of guidelines, based on ethical decision-making principles for care of patients with ESRD, is an appropriate manner in which to continue this process.

# THANK YOU

